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ABSTRACT

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BIOETHICS:

NEW RESPONSIBILITY FOR HUMAN SERVICE ADMINISTRATORS

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ABSTRACT

Bioethics:
New Responsibility for Human Service Administrators

Bioethics, the combination of ethics and the life sciences in such areas as fetal research, genetic counseling, organ transplants, experimental and behavioral research, has in recent months burst upon the consciousness of the world. As controversies rage, repercussions are often borne by populations of individuals considered within the present societal structure to be "administratively available", e.g. the retarded, the institutionalized, the aged, the poor, the handicapped. The following overview highlights the poignancy with which problems and issues surface as the fields of special education and bioethics intersect and also touches upon professionals' responsibility for protection of the persons in their care.

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Bioethics:
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Ethics as the science of the ideal human character and the storm of controversy the term often evokes dates back to the days of Aristotle. Now, as then, its chief problem has always concerned the nature of the highest good. Bioethics, on the other hand, is of more recent coinage and deals with the combination of ethics and the life sciences. Such topics as euthanasia, amniocentesis, fetal research, behavior modification, genetic counseling, and transplant surgery fall under the domain of bioethics. The link between the ethics of life and the persons in whom that life resides, although alluded to in the literature of law and the medical professions is now, as in the past, surrounded by and clouded by questions and uncertainty. Exploding suddenly on Western consciousness, bioethics is a phenomenon the social scientists failed to predict. Nonetheless, it is an area, says Renee Fox, where social scientists, if they choose, could "re-become kings".[1]

A cursory glance through university course catalogues in the last five years reveals a new trend toward interdepartmental courses involving ethics, and more precisely, bioethics. As the course titles indicate--"Religion, Business and the Law" (University of Southern California); "New Biology and the Law" (Columbia); "Law and the Life Sciences" (South Carolina); "Ethics and the Law" (Harvard)-- there is emphasis on the theory of the respective disciplines but no mention of the actual persons involved. Concomitant with the growth of university courses related to bioethics is the rise of new centers in the United States to research, theorize, and offer interdisciplinary perspectives on bioethical issues, e.g. The Institute on Ethics and the Life Sciences, Hastings-on-Hudson, New York, and The Kennedy

Institute on the Life Sciences, Georgetown University, Washington, D.C.

In terms of life rather than the classroom, however, there are a number of facts, little solid theory, and often serious repercussions on persons, most notably the economically poor, military personnel, prisoners, the institutionalized, children and fetuses, the aged and the terminally ill, all of whom are considered "administratively available" within the present societal structures for participation in research.[2]

Rights: Societal and/or Individual

Some issues which surface, then, as the areas of the social sciences, bioethics and the law intersect are responsibility for the protection of persons who, even at adulthood, may possibly be incapable of making serious, far-reaching decisions on their own behalf and the concomitant question of who is the best person to make decisions of import for these persons. Rather than a cut-and-dried issue, there arises a question of balance between risk and benefit, the rights of the individual and the needs of society, and in the interpretation of individual rights. Those rights most directly affected center around privacy, autonomy and personal safety. Each of these rights may be seen as follows on a continuum between the absolute rights of the individual and the absolute rights of society:

> 1.) PRIVACY: The right of an individual to keep some aspects of his personality and behavior hidden from scrutiny-- counterbalanced by the public's need for information to build viable systems of interaction and to acquire knowledge that transcends individual self-awareness.
>
> 2.) AUTONOMY: The right of an individual to act in accordance with his own inclinations-- counterbalanced by the public's need for societal controls over individual freedom.

> 3.) PERSONAL SAFETY: The right of an individual to be free from harm or risk-- counterbalanced by the fact that no new treatment or procedure can be introduced into society without going through a period of experimentation involving, eventually, trials in man.[3]

Integral to protecting all of these rights is some resolution of what constitutes the controversial concept of "informed consent" for this has been regarded as the keystone of ethical human experimentation. There are those who believe that informed consent is an impossible ideal in regard to "captive audiences". Others believe that informed consent involves complete disclosure based on explanation, description of risks, expected benefits, alternatives, and options to question and/or withdraw, and since this is not always possible because experimentation by its very nature deals with unknowns, the whole issue becomes a contradiction in terms. The problem of informed consent, however, becomes a moot issue when dealing with persons such as children, the institutionalized or the mentally retarded who cannot give appropriate consent, and present methods of obtaining it from these persons are, at best, inadequate. In the absence of a parent or guardian to speak on a child's or incompetent adult's behalf, the courts or a review board consisting of doctors, lawyers and representatives of the general public are sometimes asked to give consent for various procedures affecting the lives of these individuals, but does this proxy "permission" constitute informed consent?

The events that most often become issues for solomonic decisions in the lives of the persons considered administratively available in terms of bioethical questions are tied to <u>life</u> itself-- its beginnings, its

quality, its continuation, its cessation. Guidelines are scarce; penalties may be numerous; and in many cases, life is at stake. The only point of agreement seemingly held by all professionals involved in decision-making at this level is that informed consent does not relieve one of responsibility; nor does the alternative of proxy permission.

Beginnings of Life

Amniocentesis, the withdrawal of fluid from the amniotic sac in order to gain information about the condition of the fetus, is being used increasingly for diagnostic purposes. By examination of the amniotic fluid a number of diseases, some of them associated with handicapping conditions, can be diagnosed in utero. This leads to serious moral questions when information gained from the process of amniocentesis might then be used to justify the termination of pregnancies which in the absence of intervention would result in the birth of a handicapped child or be used either to give a family a headstart in adjusting to and preparing for the birth of a handicapped child.

Another phenomenon affecting the potential beginnings of life for the handicapped is the area of genetic counseling. Recent decades have been marked not only by a rapid increase in services of this type, but also by a growth in the kinds of information genetic counseling can provide, such as an explanation of recessive inheritance of diseases like phenylketonuria, sex-linked diseases like hemophilia, and the dominance of such diseases as Huntington's chorea. Like amniocentesis, however, genetic counseling can be a mixed blessing. Ethical questions arise as to what are the facts, how are they to be communicated, and whether all the findings are to be communicated or only those the family may have suspected when they first came

for genetic counseling. Can knowledge gained in the field of genetics be used to lobby for mandatory genetic counseling and the ultimate regulation of who should bear children? Might the individual be sacrificed to the perceived net good of society?

Beyond genetic counseling and amniocentesis, another issue directly associated with the beginnings of life of a handicapped person is a concept euphemistically known as passive euthanasia. Parents and physicians face a dilemma when an obviously defective infant is identified at birth and requires medical or surgical attention merely to stay alive. If parents withhold consent for medical care and the physician acquiesces, the infant may die. To provide appropriate medical care, however, may maintain the existence of a being perceived by some to have only minimal capacity for personal development and human interaction.

Numerous opinions vie for credibility at every point along a continuum of those who value life whatever form it may take and those who would have the humanness of a person dependent in some way on their perceived potential or future worth. The coming to be of a handicapped person is fraught with complications. In a society that strives for normal children, the handicapped are often seen as outcasts. This results in a tension between efforts to have only normal children and the gut-level realization that this will not always happen. In these situations the care given to the abnormal children who are born can well stand as a sign of that society's humanity.

During Life

Should a handicapped person come through the birth process and the early years unscathed, additional traumas may lie ahead. Indeed, there is documented evidence to show that 150,000 American children are now being

given stimulant drug medication for learning and/or behavior problems.[4] A sizable proportion of this group may be presumed to be those children labelled handicapped, and evidence indicates that this medicating of school-age children is often for the benefit of the child's teacher or the pharmaceutical company involved rather than for the benefit of the child. A 1976 survey in a popular magazine reported that a significant majority of interviewees approved drug testing without consent on persons judged to be "unproductive" or "undesirable".[5] Handicapped populations, under one label or another, bore such pejorative labels.

Since drug testing in residential institutions for the retarded is sometimes labelled as "therapy" rather than non-therapeutic experimentation, the due process rights that are considered essential in a legal courtroom setting are not considered crucial in parens patriae (the state as parent) civil situations. Charles Halpern, the lawyer in the Partlow State School's litigation process in Alabama in the early 1970's found, in researching the case, that some institutions for the mentally handicapped carry out an odd combination of eighteenth century medicine side-by-side with a highly sophisticated program of biomedical and/or behavioral research.[6]

While advocates of the retarded once fought for the right to treatment, especially for the mentally retarded who were institutionalized, Judge Orrin Judd, the lawyer in the Willowbrook proceedings in New York rejected the right to treatment approach in the light of his findings and based the Willowbrook Consent Decree on the handicapped person's right to protection from harm.

Another issue affecting the life of handicapped women is that of sterilization. Is it a right? Can it be forced upon a woman? Can it

be imposed for the sake of convenience? What role do informed consent and proxy permission play with regard to these issues?

End of Life

As at every other stage of their lives, the handicapped meet poignant problems in relation to their death. The courts have become increasingly involved as more and more doctors seek advice on what should be done for patients who are themselves unable to choose what kind and what amount of care doctors should provide for them. It is not because of any expertise on the part of the courts that this change in emphasis has taken place, but because only judges can provide civil and criminal immunity for the actions of those who decide.

In spite of this trend on the part of doctors, the courts do not abide by a universally held opinion. While the Quinlan case decided in New Jersey, holds that relatives, physicians and hospital committees do, indeed, have the right to decide to withdraw mechanical assistance believed to be sustaining life in a comatose person, this decision did not become a binding precedent in other states. Less sure now than formerly of what death actually is, the courts in different states have gone in different directions. The Massachusetts Supreme Court in November, 1977, handed down an opinion that all decisions on removal of artificial life-support systems, the continuation or cessation of life-extending therapy in patients incompetent to decide for themselves must go before a court for approval.

What awesome power rests on the decision of the courts! Will the courts also decide in a time of scarce resources who gets the particular medical device and/or procedure, and might the handicapped in this case be forced to take a back seat? Might a physician be more willing to declare a handicapped person dead, particularly a long-time resident of

a state institution, in order to use needed organs for a transplant? Yes, in death as in life the handicapped person albeit less knowingly, faces the same problems as every other person. They experience, though perhaps in different proportions, the human condition that is a mixture of strength and weakness. This alone serves as evidence that they are no less worthy of life than is any other person. "The society which encourages only the strong and intelligent tends to forget that man is essentially weak. All are potentially handicapped, and all are called to live and die."[7]

Summary and Conclusions

In regard to bioethical issues physicians find themselves in precarious positions, legally liable for their decisions. Lawyers find themselves without precedents on which to rely. Those who deal most closely with a great proportion of the handicapped population, the human service administrators have not yet become totally alerted to the challenge that is theirs. Should they so choose, human service administrators could become the link between services and technologies and handicapped persons who would benefit from them.

Life is sacred. The handicapped person should have the opportunity to enter into his own life process as deeply as possible, experiencing what life offers-- joy, pain, goodness, suffering, and finally, death. The paramount sanctity of human life has always been at the center of western civilization, "... not merely by guarding 'life itself' however defined, but by safeguarding the penumbra, whether at the beginning, through some overwhelming disability of mind or body, or at death."[8]

Footnotes

[1]Fox, R. The American Bioethical movement: Its social and cultural meaning. Hardy Chair Lecture. Oneonta, New York: Hartwick College, February, 1978.

[2]"Experiments and research with humans: Values in conflict." Conference Proceedings. Washington, D. C.: National Academy of the Sciences, 1975.

[3]Halpern, A. S. "The impact of the protection of human subjects on research." Working Paper 70. Oregon University rehabilitation, Research and Training Center in Mental Retardation, April, 1973.

[4]Brown, B. S. et al. Behavior modification: Perspective on a current issue. National Institute on Mental Health. Washington, D. C.: Department of Health, Education and Welfare, 1975.

[5]Lewin, L. C. "Ethical Aptitude Test." Harper's. 101 (October, 1976) 20-21.

[6]"Experiments and research with humans...." (See Footnote 2).

[7]Vanier, J. "The contribution of the physically and mentally handicapped to development." Address given at the general meeting of the International Conference on Social Welfare. Nairobi, Kenya, 1974.

[8]Vanier. (See Footnote 7).

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